

Feeding Choices for People with Advanced Parkinson's Disease

Information for patients, families and caregivers

As Parkinson's disease worsens, everyday activities like eating and drinking can become more difficult. This resource explains how Parkinson's disease can cause swallowing problems and how there are different choices for feeding.

We hope you find this resource helpful.

Please ask the health care team if you have any questions.

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Learning about Parkinson's Disease

Parkinson's disease is a disease of the brain that affects movement. Not everyone experiences Parkinson's in the same way. The symptoms vary from person to person. People with Parkinson's may notice difficulty eating and drinking. While these changes can happen at any time, they tend to get worse as the disease progresses. Major difficulties tend to be seen long (more than 10 years) into the disease.

How will I know if nutrition is affected by Parkinson's Disease?

The health care team may start to look carefully at swallowing and nutrition if the patient:

- chokes or coughs when trying to eat or drink
- has trouble swallowing food or medicine
- has less appetite and/or is losing weight

How is swallowing tested?

Swallowing includes all of the steps that happen between taking a sip of a drink or a bite of food and when it gets into the stomach. When food or drink goes down the wrong way into the voicebox or lungs, this is called **aspiration**. Aspiration can lead to infection of the lungs (pneumonia).

A Speech Language Pathologist (SLP) does the swallowing test by looking at:

1. **Swallowing safety** – whether or not food or drink is going down the wrong way into the lungs
2. **Swallowing enough** – how quickly or easily a person is able to swallow different foods and liquids

The SLP may suggest a second and more detailed test using an x-ray.

What can be done if food is going down the wrong way?

There are ways to help patients who are aspirating:

1. Keep the body in a certain position during eating. For example:
 - sit with the back straight up (like in a chair)
 - keep the chin down close to the chest
2. Change food texture to **minced** or **pureed** foods
3. Change drinks to thickened liquids that cannot leak as easily into the lungs. For example:
 - **nectar thick** means the liquid is slightly thicker like a smoothie or milkshake
 - **honey thick** means the liquid is thicker like thick honey

What can be done if the swallowing problems lead to not eating or drinking enough?

There are many ways to add protein and calories in a diet:

- Drink supplements, such as Boost or Ensure
- Add protein powders, such as Beneprotein, to food or drinks
- Choose foods that are high in calories, fats and protein

What can be done if these things don't work?

If trying ways to reduce aspiration and add calories don't work, the health care team may suggest:

- **careful hand feeding**
- **tube feeding** (also called "artificial nutrition")

What is careful hand feeding?

Careful hand feeding means giving someone small amounts of food and drink when they are no longer able to feed themselves. Careful hand feeding can work as long as a person is comfortable and wants to be fed. Patients should never be force fed food.

The health care team may suggest:

- sitting upright
- reducing distractions at mealtimes
- making sure the patient swallows a bite before giving the next bite

Benefits

- Patients can continue to taste and enjoy their favourite foods
- Patients can enjoy being around loved ones during mealtimes
- Better oral health and less pain from a dry mouth and throat
- No problems from inserting a feeding tube (see page 6 to learn more)

Possible problems

- May increase the chances of food going down the wrong way (aspiration) that could lead to a lung infection called **aspiration pneumonia**
- Patients may have pain when breathing or coughing if something goes down the wrong way
- Patients may not eat enough by mouth
- It can take a long time for patients to finish a meal

What is tube feeding?

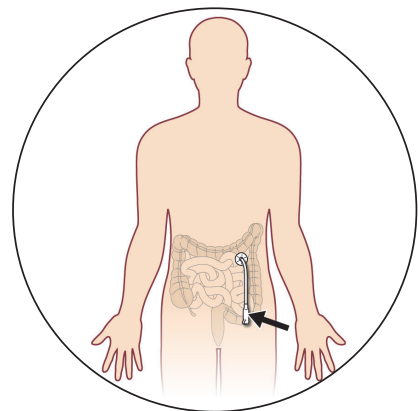
Tube feeding is a way of giving food and fluid to a patient who cannot eat or drink enough on their own. Liquid food and fluid are put into the stomach through a tube.

If you and the health care team decide to use tube feeding, there are 2 types of tubes:

1. **A nasogastric tube** or “NG tube” is a thin plastic tube that goes into the nose, down the throat and into the stomach. NG tubes are only used for a short period of time, usually less than 6 weeks.



2. **A gastrostomy tube** or “G tube” is a plastic tube that is inserted during a short operation. The tube is put through the skin of the belly so that it enters right into the stomach. G tubes can be left in place for a long time.



Once an NG tube or G tube is in place, liquid food, fluids and medicine can be put into a container and attached to the tube. The liquid can then travel down the tube and into the stomach.

Benefits

- Will give the patient enough calories if their stomach can absorb nutrition
- Takes less time to feed so there is more energy left for other activities
- Medicines can also be given using the feeding tube

Possible problems

- Having the tube put in a patient's nose or stomach can be painful.
- The tube may cause a patient to become agitated, which may need to be controlled with medicine or physical restraints
- The tube could get pulled out
- The site of the tube may become infected
- The tube could get blocked with food or medicine
- Tube feeding may cause stomach pains
- Tube feeding sometimes causes diarrhea
- Food from the tube can still get into the lungs and cause an infection, called aspiration pneumonia
- Tube feeding can make mealtimes less enjoyable
- Tubes need to be checked and maintained many times in a day

We do not know enough about how tube feeding affects patients with Parkinson's. There are only a few studies of patients with Parkinson's disease who decide to try tube feeding. We do not know yet if tube feeding prevents weight loss or improves a patient's everyday life.

Important: When someone is tube fed it may or may not improve their quality of life or help them to live longer. It may not prevent a lung infection (aspiration pneumonia).

Who decides which feeding option to use?

After speaking with the health care team, the patient decides. The patient can only decide if they understand the risks and benefits of each choice.

Because swallowing problems often happen at a late stage of Parkinson's disease, when memory and decision-making can also be affected, we encourage patients with Parkinson's disease to think about what they would want to do if they experienced swallowing problems. Patients with Parkinson's disease can let their substitute decision-maker and/or the health care team know their wishes in advance.

The patient's substitute decision-maker would choose the feeding option if the patient is unable to make this decision.

The health care team wants to make sure you understand the risks and benefits of each option and the possible results of each option.

Can a patient decide to stop tube feeding?

Feeding tubes can be removed when they are no longer needed or when they are causing more harm than good.

The health care team may talk to the patient about stopping tube feeding when:

- Tube feeding seems to be causing more pain than relief
- Tube feeding starts causing health problems
- Tube feeding has not improved the patient's health
- Tube feeding is no longer leading to a meaningful improvement in quality of life
- The patient receiving tube feeding or their substitute decision-maker would like to stop tube feeding for any reason

Some people may be worried that stopping tube feeding makes a person die sooner. **Stopping tube feeding is not done to make someone die sooner.** When it becomes more harmful than helpful, it is OK to stop tube feeding.

Will a patient feel hunger and thirst without tube feeding?

There are no studies that look at hunger and thirst in patients with advanced Parkinson's. Generally, as people reach the end of their life, the body begins to feel less hungry and thirsty. People who feel hungry feel better when they eat very small amounts of food by careful hand feeding. People who feel thirsty feel better when they have ice chips, liquid on mouth swabs, small sips of liquid or when their mouth is wet.

Will death come sooner if a patient does not choose tube feeding?

It is difficult to know if tube feeding helps patients with Parkinson's disease live longer. This may depend on how far along the disease is when swallowing problems begin (and whether the patient has other medical problems).

Tube feeding may not improve quality of life. It is important to consider the patient's wishes when making decisions about feeding.

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